

# Patient, Caregiver, and Physician Perspectives on the Burden of Disease Chronic Refractory Gout and its Treatment: Concept Elicitation

Angelo Gaffo, MD<sup>1</sup>, Bhavisha Desai, Pharm D<sup>2</sup>, Abiola Oladapo, PhD<sup>2</sup>, Nana Kragh, MSc<sup>3</sup>, Rebekah Zincavage, PhD<sup>4</sup>, Brad Padilla, MPH<sup>4</sup>, Naomi Schlesinger, MD<sup>5</sup>

<sup>1</sup>Division of Rheumatology and Clinical Immunology, University of Alabama, Birmingham, AL, USA, <sup>2</sup>Sobi Inc., Waltham, MA, USA, <sup>3</sup>Sobi, Stockholm, Sweden, <sup>4</sup>Stratevi, Boston, MA, USA, <sup>5</sup>University of Utah, Salt Lake, UT, USA

PCR211

## CONCLUSIONS

- This is the first study to the authors’ knowledge to evaluate caregiver burden along with those of physicians and patients in chronic refractory gout (CRG), also called uncontrolled gout (UG)
- Patients, caregivers, and physicians reported substantial burden and impact associated with UG and its treatment on health-related quality of life (HRQoL) and activities of daily living
- Caregivers highlighted challenges that they face, particularly those related to finances and employment
- All participants stated lack of efficacy, side effects, and challenges associated with treatment regimen were key treatment burdens, suggesting the need for new efficacious and convenient UG treatments

## BACKGROUND

- Patients with uncontrolled gout (UG), also known as chronic refractory gout, fail to achieve or maintain normal serum urate levels (<6mg/dl) and have uncontrolled symptoms despite the use of oral urate-lowering therapies (ULT), or suffer from comorbidities that preclude their use of conventional therapies<sup>1,2</sup>
- Studies on treatment experiences, decision-making, barriers, and the impact of UG on patient lives from the perspectives of patients, caregivers, and physicians are limited
- This research explored the treatment experiences, burden, and impacts of UG on HRQoL of patients, caregivers, and physicians who treat UG

## OBJECTIVES

- The objectives of this qualitative research were to:
  - Identify key concepts central to understanding patient and caregiver experiences with UG, including the impact of UG on daily lives, HRQoL, well-being, and caregiver burden
  - Understand patient and caregiver perceptions regarding their treatment experience with UG, including burden of treatment and factors driving treatment decision-making
  - Explore physician perspectives on patient disease burden, treatment burden, factors involved in treatment choices and decision-making, and barriers to treatment

## METHODS

### Study Design

- Qualitative 60-minute interviews were conducted from April to May 2024 with adult patients, informal (unpaid) caregivers, and physicians who treat patients with UG; output from this concept elicitation interview will inform the development of the survey tool to be used in a broader sample of patients, caregivers and physicians
  - UG was defined as a history of symptomatic gout, defined as: ≥2 gout flares within 12 months OR presence of ≥1 gout tophus OR current diagnosis of gouty arthritis; AND either currently taking a ULT agent (i.e., xanthine oxidase inhibitor, uricase, probenecid) OR previously received treatment with pegloticase in the past 18 months
  - Informal caregivers were adults currently taking care of an individual (≥18 years old) who has been diagnosed with UG; professional caregivers were excluded
  - Physicians were currently treating a minimum of 5 patients with UG
- Patient and caregiver interviews examined UG’s impact on HRQoL, adherence, factors driving treatment choices, treatment experiences, physician interactions, and caregiver burden
- Physician interviews assessed patient experiences, interactions, and treatment burdens/barriers
- All interviews were coded in ATLAS.ti and thematically analyzed within and across the three groups

## RESULTS

### Participant Demographics

- 6 patients, 4 caregivers, and 8 physicians (5 nephrologists; 3 rheumatologists) completed interviews
- Participant demographics are presented in Table 1 and Table 2

Table 1: Patient and Caregiver Demographics			
	Patients (N=6)		Caregivers (N=4)
Median age, years (Range)	54.0 (40.0, 72.0)		50.5 (44.0, 60.0)
Gender, n (%)			
Male	5 (83.3)	0 (0)	
Female	1 (16.7)	4 (100)	
Ethnicity, n (%)			
White	4 (66.7)	4 (100)	
Black	2 (33.3)	0 (0)	
Caregiver's relationship to patient, n (%)			
Spouse	n/a	3 (75.0)	
Mother	n/a	1 (25.0)	
Region of residence, n (%)			
Northeast	2 (33.3)	1 (25.0)	
Southeast	3 (50.0)	1 (25.0)	
Southwest	0 (0)	1 (25.0)	
Midwest	1 (16.7)	0	
West	0 (0)	1 (25.0)	
n=number of participants, N=total number, n/a=not applicable			

Table 2: Physician Demographics		
Physicians (N=8)		
Years of experience		
Median (Range)	13.0 (4.0, 28.0)	
Primary specialty, n (%)		
Nephrology	5 (62.5)	
Rheumatology	3 (37.5)	
Region of residence, n (%)		
Northeast	4 (50.0)	
Southeast	2 (25.0)	
Southwest	1 (12.5)	
Midwest	1 (12.5)	
Setting of practice, n (%)		
Private practice	4 (50.0)	
Academic hospital	4 (50.0)	
Practice location, n (%)		
Suburban	5 (62.5)	
Urban	3 (37.5)	
n=number of participants, N=total number		



### Impact of UG on HRQoL and Activities of Daily Living

- Participants commented on the wide-ranging impacts to patients’ lives due to the severe pain and limited functionality associated with gout flares, such as inability to stand and bear weight, restricted mobility, mental health issues, inability to work and complete daily activities, and financial impacts due to the high cost of care (Figure 1)
- While patients emphasized the impacts of UG on their physical and emotional health, caregivers often highlighted the financial burden and the impact on patients’ ability to engage in daily activities



### Caregiver Involvement

- All physicians reported that caregivers can play an important role in care
- Caregivers experienced stress due to various factors, including managing the patients’ medications, providing support to someone in pain, worrying about the patient receiving necessary treatment, and fearing that their actions could cause their family member pain
- Caregivers cited absenteeism, stress, physical impacts, disrupted routines, and time lost due to traveling to appointments and treatment sessions as challenges they face while caring for a patient with UG

### Caregivers

“You know, if he has a flare up I have to get it if something happens. For example, I was in the middle of seeing clients and if you have 10 people lined up and you're seeing them all day, that could be \$1,000 a day. That's the difference of me making the house payment... You lose all that pay.”

“So there I'm staying up. Then until after 10 [pm] to make sure he takes the medication. And yeah, that affected my emotional and mental well-being for 48 hours, so all pretty stressful.”



### Interactions with Physicians

- Some patients felt excluded from the decision-making process, while others actively sought information about treatments and engaged in discussions with their physician
- Generally, patients had mixed reactions regarding how they perceive their care
  - About two-thirds of patients felt their providers understood them and listened to them
  - Approximately one-third of patients were dissatisfied with their physician’s level of understanding of their condition and/or its impacts

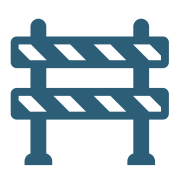
### Patients

“I don't think [providers understand what I am going through with my gout]... Because they don't have to live it... I think you know, I go to the doctor and just leave it up to them. And what their professional opinion was. But I don't think outside of the one most of them had never suffered from it, so they couldn't really relate to it.”

“...I think he does, for the most part he understands. ... I mean, I couldn't stand when he saw my feet .... So I don't think they understood by phone when I was telling him by phone. But when he saw my feet, he understood.”

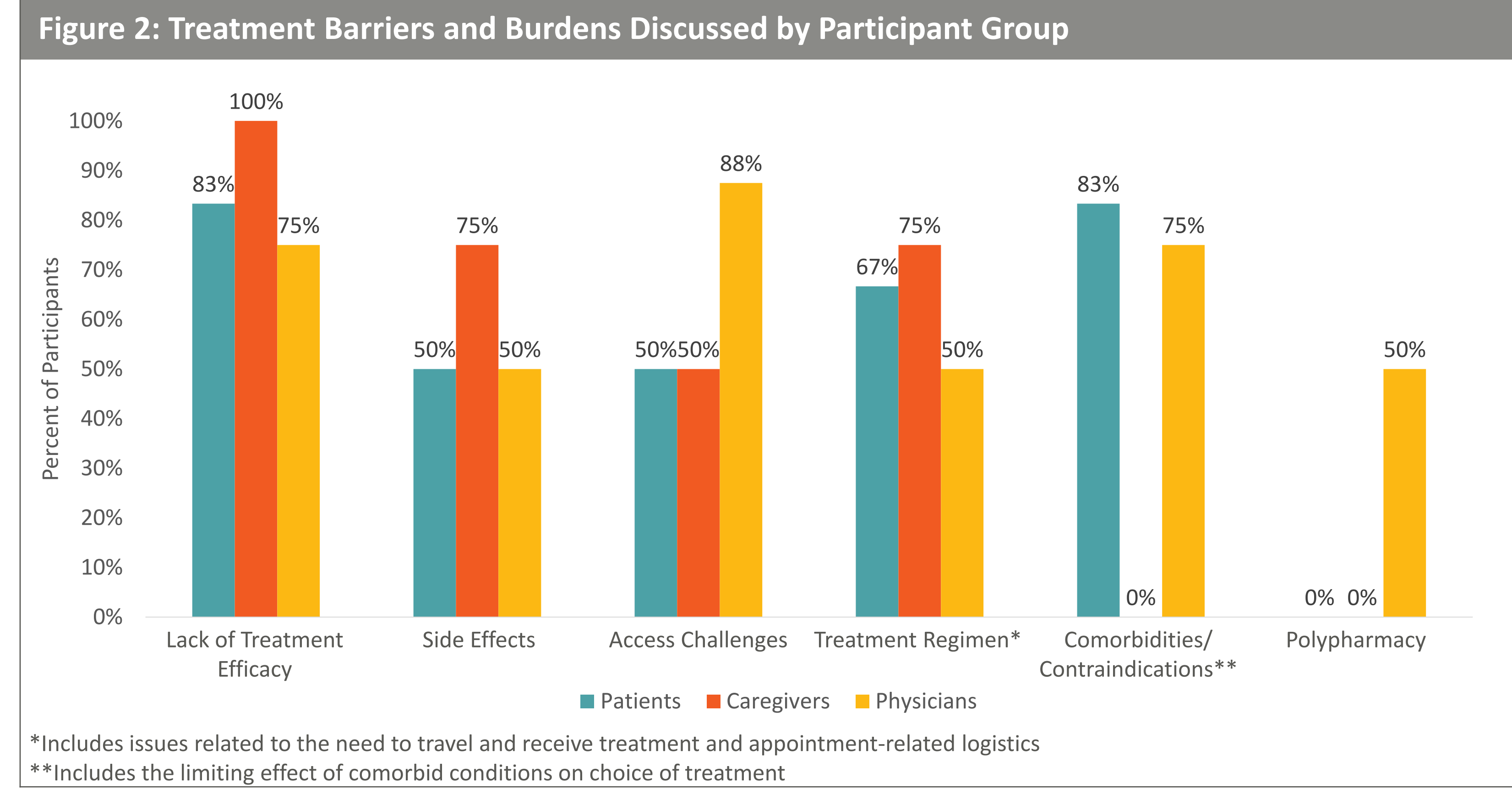
### Caregiver

“The first doctor that he went to for his gout, she did not care. And she was a, she was a doctor, doctor. She just threw prescription at him basically said I'll see you in three months.”



### Treatment Barriers and Burdens

- The most common treatment burdens cited by patients, physicians, and caregivers were lack of treatment efficacy, access challenges, and difficulties related to the treatment regimen (Figure 2)



### Patient Perspectives on Treatment Decisions

- Half of the patient sample (n=3) noted that side effects were the most important factor in making treatment decisions; this was consistent with the burden of kidney, liver, spleen, and gastrointestinal side effects they described
- Patients who reported discussing stopping treatment with their physicians (n=3) also emphasized that they are actively involved in their own treatment decisions

### Patients

“Bowel movement, upset stomach, my stomach hurt real bad ... That colchicine made me sick at first.”

“I want to have an ultrasound or I want a CT showing that tophi, those crystals ... So I want to see now ten months later, do we still have that, or is it all gone? If it's gone, then is it necessary to continue the [medication]?”

“He wanted to put me right back on allopurinol after that episode, and that's why I went on probenecid because I said no, absolutely not.”



### Physician Perspectives of Management and Treatment Decisions

- Physicians emphasized adherence and lifestyle changes as essential steps for UG management
- Beyond efficacy and safety, physicians stressed individual patient circumstances, disease severity, patient receptivity, medical history, and cost/access as other important factors in making treatment decisions

### Physicians

“And again, they're mostly questioning what side effects may occur ... Some will ask, does this interfere with my other medications? Is it compatible with my other medications? So that would be about the scope of the usual patient questions about the initiation of therapy.”

“I mean, whether they're open to it or not, they hear it anyway from me, whether they abide by, it is another matter ... You can see it in their demeanor, in their face and their lack of interest in what you're saying. But they listen to it. But you can tell that they're not receiving it.”

## LIMITATIONS

- Interview data collection relied on qualitative, self-reported information
- Generalizability to broader UG population is limited
- Social desirability bias could have influenced participants' responses
- Findings from this study should be further explored throughout quantitative methods

### References

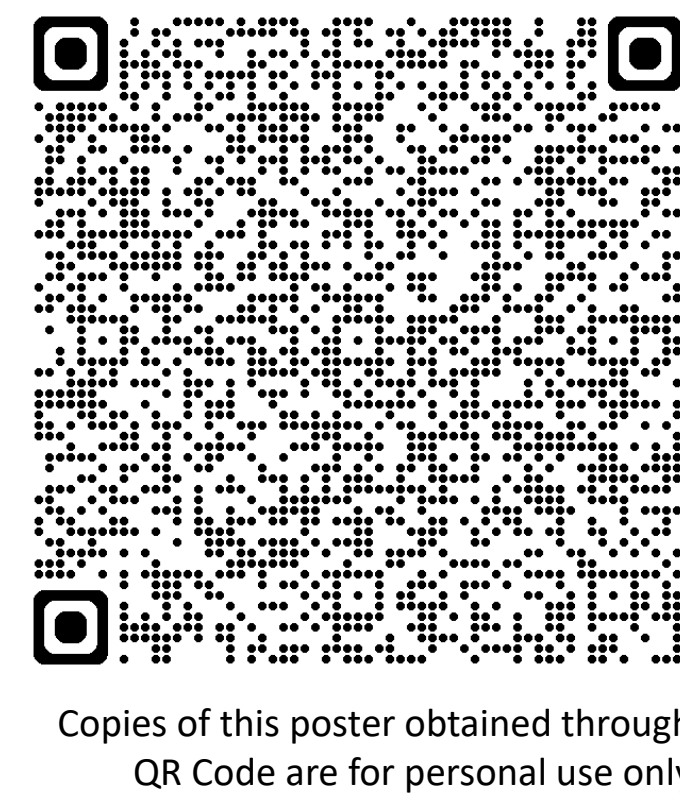
- Fels E, Sundry JS. Refractory gout: what is it and what to do about it? *Curr Opin Rheumatol*. 2008;20(2):198-202.
- Francis-Sedlak M, LaMoreaux B, Padnick-Silver L, Holt RJ, Bello AE. Characteristics, comorbidities, and potential consequences of uncontrolled gout: an insurance-claims database study. *Rheumatology and Therapy*. 2021;8(1):183-97.

### Acknowledgements

This poster was created by the authors in accordance with Good Publication Practice (GPP) 2022 guidelines (<https://www.ismpp.org/gpp-2022>). The authors would like to thank Diane Ito for her oversight throughout the study and Maggie O'Grady for supporting the development of this poster. Sobi reviewed and provided feedback on the poster. The authors had full editorial control of the poster and provided their final approval of all content.

### Disclosures

This study was sponsored by Sobi Inc.  
AG: Consulting: Sobi, PK Med, Atom, Avalo Therapeutics, Scilex.  
BD, NK, AO: Employee and/or shareholder: Sobi.  
RZ, BP: Employee: Stratevi, a research consulting company, receiving funding from Sobi to conduct this study.  
NS: Advisor or Review Panel Member: Olatec, AMGEN, Protalix, Sobi, Shanton, Arthroci, Scilex.



Copies of this poster obtained through QR Code are for personal use only